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Editorial

Reframing the conversation on patient experience: Three considerations

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Abstract

In experience, every voice matters, and each of those individual voices are contributing to an ocean of ripples that are positively impacting countless lives. In experience, no one organization owns, nor should claim to own all the answers, but many contribute to the possibilities found in elevating the human experience in healthcare. In experience, when we ensure this is a true strategic focus at the heart of healthcare we will find our way to achieving all the outcomes we aspire to achieve and know are possible in healthcare. This issue helps frame that reality through contributions from around the world touching on a broad range of topics, but yet in their distinction, find a powerful commonality, a commitment to the humanity of healthcare. If we reframe the conversation on patient experience to one that is about all we aspire to achieve, about how every role matters, every voice contributes, every perspective brings value and seasoning to an ever expanding mix of possibility, than what we can do in healthcare is boundless. A conversation on experience is not tangential to this opportunity we face, rather it rest squarely at its core and it is incumbent on each and every one of us to contribute. That may be our greatest opportunity in a global healthcare system where access and equity, quality and safety, empathy and compassion and health and well-being are not just what we do as work, but the fundamental reality of all do as human beings caring for human beings.

Keywords

Human experience, patient experience, global healthcare, interaction, quality, safety, systems thinking

Moving to a State of Action

As we release the first issue of Volume 6 of *Patient Experience Journal*, I remain amazed, enlivened (and truly not surprised), by the generosity of spirit, contribution and connection exemplified by the global patient experience community. With well over 400,000 article downloads from PXJ globally, the contributions of our hundreds of authors to the hundreds of thousands of readers who are impacting the lives of millions in healthcare organizations and systems globally all reinforce one simple fact. In experience, every voice matters, and each of those individual voices are contributing to an ocean of ripples that are positively impacting countless lives. In experience, no one organization owns, nor should claim to own all the answers, but many contribute to the possibilities found in elevating the human experience in healthcare. In experience, when we ensure this is a true strategic focus at the heart of healthcare we will find our way to achieving all the outcomes we aspire to achieve and know are possible in healthcare.

This issue helps frame that reality though contributions from around the world touching on a broad range of topics, but yet in their distinction, find a powerful commonality, a commitment to the humanity of healthcare. The expanding conversation on humanizing healthcare are not necessarily new, it is grounded in the art of medicine though sometimes lost in its science, it has been recognized as essential to an organization's strategic success, in healthcare or otherwise, but at times downplayed in their operationalization. This is not, nor has it been done with malintent, but rather in the desire to better control circumstance and outcomes. And protocols for safety or quality operations are not and should not be seen as negative choices, yet what people expect and call for in organizational life and especially in healthcare is a recognition of the humanity on which these organizations and systems are built. William Osler, so aptly said, "Ask not what disease the person has, but rather what person the disease has."

This idea was also on display as I watched the patient experience community gather for Patient Experience Conference 2019 earlier in April around the theme "To Care is Human", reinforcing the idea that in the industry and practice of healthcare, care for the health and well-being of the person in front of us in essential. This is not simply clinical care, but care as a broader action, one human being to another; one defined as "to feel interest or concern".

But it is and must be even more than feeling. The concept of empathy, our ability to take the perspective of and feel the emotions of another person, is essential to healthcare, but this reflects only part of the perspective. In fact this represents a view from the inside out in healthcare. It is one of understanding. If we want to truly move the

conversation on experience, on caring to action it comes in elevating compassion, when the feelings or thoughts unveiled through empathy include the desire to help, to do something about it. Compassion is taking action. Elevating compassion reinforces that in healthcare we do more than feel for you, but we walk with you.

Three Considerations

The idea of moving to action is what presents a significant opportunity to reframe the experience conversation on patient experience overall. In undertaking two significant inquiries into how experience is perceived and enacted in the last year some core ideas and key themes emerged. The insights while perhaps not surprising at a human level, still push at the seams of healthcare in terms of how it has been structured and chosen to operate for many years. While often seen as a delivery system, those very words convey a provider and a recipient. And while one cannot argue there is a transactional nature that will always be part of healthcare, the experience it conveys does not require that healthcare is transactional in being. Consumers said that of greatest importance to them was being listened to, communicated to clearly in a way they could understand and to be treated with courtesy and respect.[1] I think is safe to say this is our hope for any human interaction we have. The implications of this desire though are much greater than healthcare has shown in its actions. And these ideas will drive healthcare's successes operationally and clinically, financially and reputationally.[2]

This was further reinforced in To Care is Human[3] where it was revealed that not only high performing healthcare units, but those engaged in healthcare in general acknowledged that listening and communication topped the list of factors influencing positive experience outcomes. This exploration further elevated the almost equal importance that teamwork and caring for the care team had in ensuring success. This balance of caring for the human beings in the healthcare equation calls for thinking beyond a delivery or transactional mindset, to a relational mindset. As I share in the paper, "While it is understood that much of what is encompassed by healthcare and what makes it a unique industry is the science of medicine, the resulting engineering of care and care processes has in its own way dampened the humanity in healthcare itself."[3, p.22] In elevating compassion and acknowledging the evidence that shows a true focus on the human experience at the heart of health will lead us to safe, reliable, compassionate and viable healthcare system, there are three ideas we must not only consider, but choose to act on in reframing a conversation on experience:

1. **Experience must be seen and acted on as an integrated effort.** The idea that experience reaches well beyond the concepts of service and the implementation of amenities is not new.[4] But yet far too many healthcare conversations still identify the concept of experience as separate from other points of focus, such as quality or safety. This perpetuates that idea that experience is simply the service provided and minimizes the perspective that those receiving care bring to healthcare themselves. Healthcare has operationalized itself to manage these concepts as distinct workstreams, but if one looks at the work of healthcare from the eyes of those who experience it, quality, safety, service, cost, access, equity and more are ALL part of what one experiences in healthcare. These points of focus in total shape the perspectives people bring to care and the decisions they make both in choosing where to seek care and deciding how to personally engage. To ensure experience excellence, to elevate the humanity in healthcare we cannot diminish its place or its importance, or relegate it to the just one of many things we do. If we do, we perpetuates a one way perspective of healthcare from the inside out.

2. **Experience must move beyond an inside-out perspective.** To achieve a true integrated view of experience we must acknowledge we have traditionally viewed the topic and addressed the opportunities it elevates from an inside-out perspective. The concepts of centeredness and engagement are critical approaches essential to healthcare success, but in their very vernacular they perpetuate a perspective of doing to or for. Ideas such as "we put patients at the center" or "we work to engage patients and families", are without question necessary actions to drive partnership in care. Yet, at the same time these inside-out versus outside-in perspectives run the risk of healthcare determining what those actions should and must be versus asking what those efforts could be to ensure those are served (and equally those who serve) feel as if they are true partners in the process. This shift ensures people have a sense of ownership and even control in a way that does not undermine clinical and quality excellence. Rather with an outside in perspective, the total sense of what experience can be in partnership ensures that excellence can be best achieved. This shift in perspective is achieved at the touch point between people, one human being to another.

3. **Experience must be owned at the point of interaction.** The first words in the definition of patient experience express that experience is "the sum of all interactions".[4] These interactions happen between two people either in person or in

increasing ways virtually in healthcare. This underlines the reality that experience is tactile, experience is real, and it is personal. The very data consumers and high performer alike shared suggests this. Experience is not some esoteric concept. It is also not just a disconnected list of tactics or practices. To be effective at the personal moments there must be a system in place to encourage their success. This comes in the form of strategic framing and resources and a web of support in people, processes and more that ensure those interactions are clear and effective. Be they an interpersonal moment of need, a clinical interaction ensuring quality, a tactical interaction to ensure safety, these all are essential, and they all happen at the central point of interaction. And they can only be successful if the network of support exists to ensure they are.

Fostering the Systemic Perspective

When brought together these considerations reinforce that healthcare is an ever moving blend of the art of our humanness with the science of medicine. To effectively succeed then we need to manage the points of interaction and ensure the system around them to support success. This commitment to broader considerations, to true systems thinking[5], becomes essential in our ability to better understand all the factors impacting the global health system, the practices engaged in locally and the opportunities that healthcare has overall for constant improvement.[6]

This idea was manifested in many ways as I engaged with people at The Beryl Institute's Patient Experience Conference 2019, which brought together individuals from six continents who champion experience in their own countries, regions and localities to tackle the specific needs they have. Often these individuals, in the daily work of healthcare, and especially in the experience space, feel alone or potentially disconnected. What was experienced in their coming together for something bigger, something not about an organization or a model, a product or a service, but rather an idea and a possibility was powerfully and palpably energizing. As is often the reflection of those who have the opportunity to move from individual practice to a supportive community space, the statement of "I no longer feel alone in this work" is ever present. It also remains a core purpose of efforts such as building the global patient experience community and even resources such as this very journal.

This sense that people gain, not just in physically coming together, but in virtually connecting in community, in a true system of support raises powerful realizations and presents catalysts for renewal, new learning and greater possibilities. For all that champion this work, you are not alone. And while you may at times feel like a small voice or as one individual shared, "an island in their health system", where strength can be gained, support garnered and evidence found is in the connection and coming together as community and as a ecosystem[7] of individuals, organizations, communities and nations who understand and are committed to the best in experience and therefore the greatest possible outcomes.

A View of Volume 6

This idea of coming together with diverse perspectives and varied points of focus, yet with common purpose again reveals itself on the pages of Volume 6, Issue 1. From personal narratives to global cases, disease specific interventions to national programs, the pages of Issue 1 underline the very idea that the experience conversation is both broad and deep. It also reinforces the power of coming together, of sharing resources, of community and the possibilities that are created in our capacity to share our learning and learn from what is shared.

From the power of personal stories and the reflections found in these experiences, Jennifer Cademartori of UCSF shares a powerful narrative of her experience with and expectations of healthcare as one who has worked in it. She offers us a gift from her observations of how we must recognize that "patients are the 'customers' receiving the care, but they, unlike customers at a retail store, are vulnerable and scared and must trust their lives in the hands of people they don't know."[8, p.6] She calls on healthcare to focus on the capacity it builds in all who serve to be present and focused on experience at the best and worst of times.

From the power of personal experience the need for understanding how we tackle the richness and diversity of humanity the walks through the doors of healthcare organizations daily, a powerful piece from Université Laval, Québec, on engaging patients who are ethnolinguistically diverse helps readers see the importance of perspective and awareness of perspective, both theirs as potential care providers and those they serve. More so this piece highlights a critical point elevated in the data of both the consumer study and *To Care is Human* revealed above; patients most often want to participate in their healthcare encounter and the evidence supports its value in engaging people, ensuring adherence to healthcare plans and ultimately driving better outcomes.[9]

This issue also engages in the topic of participation at a deeper and more systemic level as well, exploring the powerful use of experience-based design[10] offered by the team at Virginia Mason and the application of journey mapping to better understand actions needed to address the issue of heart failure[11] from the team at St Vincent's

Private Hospital Sydney, Australia. Both of these concepts address the powerful blend of systemic perspective and action blended with the acknowledgement of personal interaction and the individual voice. The power of voice is explored in a series of articles as well that delve into measurement, from online questionnaires[12] to the challenges of responses rates currently being experienced with the government mandated surveys in the United States.[13]

Beyond the voices of those served by healthcare, this issue continues to reinforce the power of systemic perspective by addressing two other issues elevated at the heart of healthcare, one process-based addressing the challenging issue of wait times and one people-based in the very experiences provided those who deliver care every day. On wait times two perspectives are offered, one from Canada in which the exploration of the challenge of Emergency Department wait times is not just an academic issue, but one at the heart of public policy as well.[14] The second case digs into the tactics applied by New York-Presbyterian in the powerful application of volunteer processes in pediatrics.[15]

Three of our articles this issue delve deeper into the work on and between healthcare professionals themselves. In exploring this issue internationally both from a cross continuum and interprofessional lens, the cases around coaching between physicians presented by Scripps[16], caregiver engagement from Sinai Health System & University of Toronto[17] and interprofessional collaboration from MD Anderson[18] show the range and scope of the humanness of healthcare. These articles reinforce the dynamic nature of experience that cannot solely focus on those who receive care to be effective. The experience conversation is truly one on human experience in which efforts must care for those who deliver care and support the delivery of care as it does the patients, family and their support networks they serve. This may be no better tied together than in the case presented by NHS England and their efforts on ensuring Always Events®[19] and creating a model that includes all voices in driving for the best overall outcomes.

Reframing the Conversation on Patient Experience

The ideas I shared above about moving to a state of action, about considerations for action and about the systemic perspective we will need to succeed in rapidly growing and dynamic global healthcare system we now find ourselves in is brought to life on the very pages that follow. If we were to believe patient experience is as many had originally viewed it, as just a focus on service or even more basely one that was purely about satisfaction, this issue of PXJ and the ideas I shared above point us in a very different direction. The conversation on patient experience is truly a conversation on the human experience that all people engaged in, by and through healthcare have. It is though this expanded, active and living perspective that we will truly realize the greatest outcomes in healthcare.

If we are willing to step past our traditional models, beyond the lessons of our training to the realities of the world in which healthcare now operates and with the recognition of the expectations now placed on healthcare as an industry, there is truly one choice. If we reframe the conversation on patient experience to one that is about all we aspire to achieve, about how every role matters, every voice contributes, every perspective brings value to an ever expanding mix of possibility, than what we can do in healthcare is boundless. Yes, there will remain system constraints, but those are meant to be pushed. Yes, we will still struggle with time, the weight of processes and even the slowness of bureaucracy, but those are issues not of nature, but one created by the people who have built healthcare and therefore we can and should be the ones to change it.

A conversation on experience is not tangential to this opportunity we face, rather it rest squarely at its core and it is incumbent on each and every one of us to contribute. That may be our greatest opportunity in a global healthcare system where access and equity, quality and safety, empathy and compassion and health and well-being are not just what we do as work, but the fundamental reality of all do as human beings caring for human beings.

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